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Bernsen, RAJAM; de Jager, AEJ; van der Meche, FGA; Suurmeijer, TPBM

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How Guillain–Barré patients experience their functioning after 1 year

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Objective – To analyze how the patient himself perceives his physical and social situation 1 year after Guillain–Barré syndrome (GBS). *Material and method* – The Dutch patients who participated in an international multicenter trial were asked to complete a self-administered questionnaire containing questions on their physical status at homecoming and at 12 months, as well as questions dealing with various aspects of their social condition. *Results* – Ninety patients participated. Up to 72% had sensory disturbances and loss of power in part of the arms and up to 89% in part of the legs at homecoming. At 12 months, a significant improvement had occurred, but residua were perceived in 36 and 67%, respectively. The residua ranged from irritating to seriously disturbing in up to 49%, and only 33% felt completely cured. Furthermore, 32% had changed their work due to GBS, 30% did not function at home as well as before and 52% had altered their leisure activities. *Conclusion* – One year after the onset of GBS, a considerable number of patients still perceived a decrease of power and sensation with an often disturbing effect. GBS had an evident impact on daily life and social well-being.

Robert A.J.A.M. Bernsen[1], Aeiko E.J. de Jager[2], Frans G.A. van der Meché[3], Theo P.B.M. Suurmeijer[4]

[1]Department of Neurology, Jeroen Bosch Hospital, 's-Hertogenbosch, the Netherlands, [2]Department of Neurology, University Hospital, Groningen, the Netherlands, [3]Department of Neurology, Erasmus University Medical Center, Rotterdam, the Netherlands, [4]Department of Health Sciences/Northern Centre of Healthcare Research (NCH); Department of Sociology/Interuniversity Center for Social Science Theory and Methodology (ICS); University of Groningen, Groningen, the Netherlands

Key words: Guillain–Barré syndrome; impact; daily life; perception; functioning; social

Robert A.J.A.M. Bernsen, Department of Neurology, Jeroen Bosch Hospital, PO Box 90153, 5200 ME 's-Hertogenbosch, The Netherlands
Tel.: +31 73 6992350
Fax: +31 73 6992832
e-mail: r.bernsen@jbz.nl

Although several reports describe the patient's physical situation 1 year after the onset of Guillain–Barré syndrome (GBS), little is known about how the patient himself views his physical and social situation. Such knowledge would provide a better insight into the impact GBS can have on the life of the patient (1). Also in clinical practice the patient's view 1 year after onset is a milestone in the process of their recovery. Several personal reports (2, 3) relate how individuals experience the acute phase of the ascending paralysis and the period of artificial respiration, and how they cope with the possibility of prolonged rehabilitation. Although more attention has been given recently to the social aspects of immune-mediated neuropathies and especially GBS (4, 5), no systematic study has reported extensively on the patient's personal clinical judgment 1 year after the onset of GBS.

We studied how a group of patients experienced their physical and social situation at homecoming and at 1 year after the onset of GBS.

Material and methods

Study population

The patients participated in the Dutch segment of an international, multicenter, double-blind, placebo-controlled trial comparing treatment with intravenous immunoglobulin (IVIg) 0.4 g/kg body weight and placebo with treatment of IVIg combined with methylprednisolone 500 mg/day for 5 consecutive days (6). All patients fulfilled the NINCDS criteria for GBS, experienced onset of weakness within 2 weeks and were unable to walk independently for 10 m. An exclusion criterion in the present study was age below 16. Patients from outside the Netherlands were excluded because the testing material used was only available in Dutch. All participants signed an informed consent form with respect to our study, and the ethics committee of the participating Dutch centers approved the protocol.

Of the 125 patients who were eligible for the trial, six did not give informed consent, three

died before the trial was completed, two were too ill to participate, one suffered from an other handicap and 23 were lost during follow-up. A total of 90 patients finished the present study.

Questionnaire

A self-administered questionnaire was sent to the patients 12 months after the diagnosis of GBS was made (7). The questionnaire contained questions on the patients' discharge from one hospital to another hospital, to a rehabilitation center or to home. Six questions enquired at the presence and extent of sensory respectively motor residua in face/chest, arms and legs at homecoming. The patient could indicate if no residua were present (score = 0); only present in fingers (score = 1); present in hand and fingers (score = 2); present in arm and hand and fingers (score = 3). Lower limbs were scored in a similar way. Presence in face, chest or both resulted in scores of 1, 2 and 3, respectively. The answers to the six questions on the physical condition at homecoming were combined to an index, the homecoming index, scores running from 0 to 18. The index scores were divided in three groups: normal or mild, scoring 0–6; moderate, scoring 7–12; serious, scoring 13–18. The same six questions were asked on the physical condition at 12 months, giving the 12-month index. Furthermore, the patients were asked to appraise the disruptive effect of the sensory and motor residua of face, arms and legs at 12 months. The possible answers ranged from not present, noticeable but not really annoying, moderately annoying to seriously annoying. The answers formed the disruption index. The method of scoring of the 12-month index and the disruption index was the same as for the homecoming index.

Other questions dealt with various aspects of their social condition at 12 months. One set of questions on employment was used to determine if the work situation had changed, e.g. the same job with fewer physical demands or less responsibility, a different job with fewer physical demands or less responsibility or no job at all. The specific reasons for GBS-related job changes were determined, e.g. decrease of power, lasting sensory changes, lack of condition, mental changes or other reasons. Other questions dealt with the changes due to GBS in the housing situation, in functioning at home and in leisure activities. A few open questions were added to give the patients a chance to make further comments or to elaborate on details.

Physical assessment

At 12 months, the patients were physically assessed using the Hughes disability scale as a functional score (8): good recovery [no neurological symptoms (F0) or minor neurological symptoms and signs and capable of running (F1)], moderate recovery [able to walk 10 m or more without assistance but unable to run (F2)], or severe residua [able to walk 10 m across an open space with help (F3) or bed or chair bound (F4)]. Further possibilities are F5 = requiring assisted ventilation for at least part of the day and F6 = dead.

General data

Data were available on age at entry, sex, presence of other diseases, possible artificial respiration during the disease and the treatment the patient had received. The general data (except for sex and age) and the data on the physical assessment were not made available to us until the data from the questionnaires of all the patients were collected.

Statistical analyses

The Fisher's exact test and ANOVA were used to determine if there was a difference between the patients who participated in the study and those who did not. With respect to differences in the final *F*-score, a Mann–Whitney test was used.

Chi-square tests/Fisher's exact test was used to compare the two treatment groups regarding the self-perception of their physical and social situation.

The Wilcoxon signed ranks test was used to establish the course of the patient's condition between the moment of homecoming and 12 months after the diagnosis. Odds ratios were determined in relation to several aspects of staying at a rehabilitation center. Logistic regression was used to study the relation of the indexes of homecoming, 12 months and disruption to several social aspects at 12 months.

Results

General information

The group of patients who completed our questionnaire consisted of 48 men and 42 women, ranging in age from 16 to 88 years. At entry, 28 patients scored F3, 56 F4 and six F5 (ventilator dependent). At nadir, 23 patients were ventilator dependent. After 1 year, 30 patients scored F0, 43 F1, 11 F2, three F3 and two F4 (one missing).

The patients who completed the questionnaire were compared to those who refused to participate and to those who did not participate due to failure in follow up. No differences were found with respect to age, sex, artificial respiration, treatment and *F*-score.

In our group of patients analysis showed no difference between those treated with IVIg and those treated with IVIg and steroids, regarding the self-perception of their physical and social situation.

Course

Fifty-six of the 90 patients (62%) were discharged directly to home after a hospital stay lasting on average 23 days with a minimum of three and a maximum of 59 days. Twenty-nine patients (32%) were discharged directly to a rehabilitation center. The mean duration of stay in hospital and rehabilitation center was 131 days, varying from 34 to 273 days. One patient went first to another hospital and later to a rehabilitation center, two stayed with family and two went to a nursing home.

Sensory changes and decrease of power experienced by the patients at homecoming are specified in Table 1. Up to 72% had sensory disturbances and loss of power in some part of the arms and up to 89%, in some part of the legs.

After 1 year, 33% of the patients felt completely cured, one within 22 days, but with a mean of 230 days after onset of GBS. Nine patients felt that their improvement had stagnated after a period lasting from 207 to 315 days (two missing values). Presence of disturbed sensation and decreased power, reported by the patients at 12 months, is presented in Table 1. It appears that a considerable number of patients still perceived decreased power and disturbed sensation, in the lower extremities more than in the upper extremities.

Table 1 Percentages of sensory disturbances and loss of power experienced by the patients at homecoming and 1 year after GBS ($n = 90$) (Wilcoxon signed ranks test, one-sided)

	Homecoming		After 1 year		Improvement	
	Disturbed sensation	Loss of power	Disturbed sensation	Loss of power	Sensation	Power
Face/chest	38.9	45.6	16.7	24.4	$P < 0.001$	$P < 0.000$
Missing values	13.3	15.6	10.0	8.9		
Arm/hand/fingers	31.1	55.6	16.7	24.4	$P < 0.000$	$P < 0.000$
Hand/fingers	21.1	11.1	10.0	5.6		
Fingers	13.3	5.6	8.9	5.6		
Missing values	4.4	5.6	6.7	3.3		
Leg/feet/toes	50.0	80.0	34.4	54.4	$P < 0.000$	$P < 0.000$
Feet/toes	20.0	5.6	15.6	6.7		
Toes	8.9	2.2	10.0	6.7		
Missing values	4.4	5.6	2.2	1.1		

Table 2 Percentage of patients with a perceived disruptive effect with respect to sensory disturbance and loss of power in face/chest, upper extremity and lower extremity 1 year after onset of GBS ($n = 90$)

	Face/chest		Upper extremity		Lower extremity	
Perceived effect	Sensation	Power	Sensation	Power	Sensation	Power
Noticeable, not disrupting	6.7	5.6	14.4	10.0	22.2	16.7
Moderately disrupting	7.8	12.2	14.4	23.3	23.3	30.0
Seriously disrupting	5.6	6.7	7.8	6.7	13.3	18.9
Missing values	7.8	6.7	6.7	2.2	3.3	3.3

The perceived disrupting effect of disturbed sensation and decreased power at 12 months is depicted in Table 2. The sensory disturbances were reported to be moderately or seriously annoying in arms (22.2%) and legs (36.6%). Loss of power was reported to be moderately or seriously annoying in 30% respectively 48.9%.

Muscle ache or cramps were still present in 45.6%. Fifty percent had other residual symptoms. Fatigue in general was not systematically assessed for but was mentioned in 17%. Problems with concentration (4%) were mentioned most frequently among a variety of other symptoms. In 15.6% some form of aid like a cane, a crutch, or even a wheelchair was used.

A significant improvement can be noted in the perceived loss of power and sensation between homecoming and 12 months following onset of GBS (Table 1). If the hospital stay lasted longer, the improvement was less significant. Duration of stay showed a significant correlation with both the 12-month index ($P = 0.000$, $r = 0.39$) and the disruption index ($P = 0.000$, $r = 0.41$), but not with the homecoming index ($P = 0.060$).

Social aspects after 1 year

Thirty-three of the 90 participants in our study had already retired before the start of the study. Of the remaining 57, 18 patients (32%) had changed their work because of GBS. Only one of these 18 patients had a job on the same level as before, nine held a job with lesser demands, and eight had not yet resumed working. Seven were declared unfit to work for more than 75%. Five were disabled for a lesser percentage. Lack of physical condition (10 patients) and loss of power (nine) were the most frequently mentioned causes of the work-related problems. Twenty-eight patients had contacted the company physician; six of them were not satisfied with the results. One felt the company

physician knew too little of the residual status after GBS, and four patients mentioned they wanted to return to work but felt restrained by the company physician. When going back to work, 34 (60%) first worked part-time.

Inability to function at home as well as before GBS was mentioned by 27 patients (30%); eight patients (9%) did not live in the same place or under the same circumstances as before.

Leisure activities had altered in 47 patients (52%). Again lack of physical condition (36) and loss of power (29) were reported to be the main reasons. Sensory disturbance (13) and mental changes (four) were less frequently noted.

After 1 year, 39 (43%) were still somewhat psychologically affected because of GBS and 15 (17%) to a greater degree.

Logistic regression of the homecoming index, the 12-month index and the disruption index in relation to the change in social aspects, showed that only the disruption index leads to a change in leisure activities ($R^2 = 0.57$, $B = 0.77$, $P = 0.013$). Logistic regression of the F-score in relation to changes in social aspects only leads to a change in the housing situation.

Rehabilitation center

Patients who had been artificially ventilated were more often referred to a rehabilitation center [odds ratio (OR) 5.75, 95% confidence interval (CI) 1.919–17.226]. Patients who had been referred to a center were less likely to be completely cured (OR 0.082, 95% CI 0.018–0.374), and had more changes in hobbies (OR 5.431, 95% CI 1.92–15.355), but not in work and housing circumstances. More of these patients functioned more poorly at home than they did before the onset of GBS (OR 0.390, 95% CI 0.154–0.984).

Discussion

A high percentage of patients experienced decrease in power and sensation at homecoming. Not only the presence but also the distribution of the decrease was significant. Up to 89% of the patients still experienced loss of power, not only in toes or feet but also, in most cases, even in the legs. Diminished power in a larger part of an extremity was present in more patients than sensory disturbance. These results signify that the patients and their family should be very well prepared as to what to expect on hospital discharge. We found, however, that these physical residua at homecoming had no effect on the social situation at 12 months.

At 1 year, the patients perceived a clear improvement compared to homecoming. However, a considerable number of patients still experienced both a decrease of power and disturbed sensation. It is difficult to compare with other studies as these report about the neurological examination and our study concentrates on the subjective feelings of the patients.

In a recently published Swedish study (9), 88% of patients were fully recovered or showed only mild residual symptoms or signs on neurological examination at 1 year. In contrast to this report, our study suggests that a considerable number of patients still experience physical residua 1 year after the onset of GBS, both with respect to the distribution as well as to the disrupting effect. The findings of Rees et al. (10) are more in accordance with our study. It is possible that the discrepancies in outcome are also the result of a varying combination of differences in age, severity of signs and the amount of axonal damage (9, 11).

The loss of power in the legs was perceived as disrupting to seriously disrupting by almost half of the patients. Table 2 shows how frequently a disrupting effect continues to occur even after 1 year. This signifies that it is important not only to establish the actual presence of loss of power but also to evaluate the perceived effect.

After 1 year, more than half of the patients continued to experience improvement. This observation confirms the findings of Fletcher et al. (12) who concluded that in a group of mechanically ventilated patients, improvement might remain clinically significant well beyond 1 year. In another group of patients, it was reported that 21% still noticed improvement after 3–6 years (4). In the group that felt completely cured, this still took an average of 230 days, confirming the prolonged course of improvement a patient has to be prepared for, even in the most optimal cases. Patients should be informed clearly about the pace of recovery in order to prevent both too optimistic and too pessimistic expectations. This is considered to be an important aspect of the quality of care provided to patients (13).

The effect of social aspects on the recovery and well-being of patients with GBS and other polyneuropathies has been receiving increasing attention (4, 14–17). Although these aspects should definitely be considered in the long run, important information came out of the present study at only 1 year after onset of GBS. For example, work had changed in 32% of our patients and leisure activities in 52%. That lack of physical condition and decreased power were the most frequent causes of these changes confirmed an earlier study (4).

Familiarity with the problem may enable the attending physician to be more supportive and limit or even prevent deterioration of social functioning within the first year after the onset of GBS. In a recently published report, some items assessing these aspects are incorporated in a new handicap scale in immune-mediated polyneuropathies (15).

Comparing the results from our present study with the results in a group 3–6 years after GBS is speculative (7). In that group, 38% changed their work and 37% reported disturbance in functioning at home, slightly higher percentages than in our group. It is possible that in the long run, patients who have not completely recovered cannot keep up with the demands on their physical condition. That would explain why lack of physical condition is frequently mentioned as a problem. Changes in housing circumstances (15%) occurred more frequently in the group 3–6 years after GBS. This could suggest that some patients who first return to their previous housing arrangements would be forced to move later. Change in leisure activities, on the other hand, occurred less frequently in the long-term study (44% compared with 52% in the present study). It could be possible that after 1 year some patients are able to catch up with their previous leisure activities, although it is not known if they can perform them with the same intensity as before. These results suggest that not much further improvement occurs with respect to the social situation after 1 year. The influence of psychological factors as anxiety and depression, as well as the quality of familial environment needs further clarification, but was not the objective of this study.

Logistic regression showed that the present physical condition as represented by the 12-month index is no evident predictor for changes in the social aspects studied. However, the perceived disruption of the physical condition is a predictor for changes in leisure time. This signifies that not only the physical condition but also its perceived effect should be considered.

In general, patients discharged to a rehabilitation center had a worse *F*-score at 12 months and had more neurological sequelae than patients going home directly. Nevertheless, the final employment situation in these patients was comparable to the situation of patients who went home directly. Possibly, a stay in a rehabilitation center successfully prepares a patient to cope with his work despite his neurological residua.

It can be concluded that a considerable number of patients in our study still perceived decrease of power and sensation with an often disturbing effect 1 year after onset of GBS. Furthermore, GBS continued to have an evident impact on daily life and on social well-being. We agree with a report by Zifko (17) that a careful neurological examination should be supplemented by information about the patient's own perception of his physical condition. This knowledge would enable the attending physician to better support the patient's recovery.

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